

Executive Summary

Executive Summary

On April 18, 2000, the late Governor Carnahan issued Executive Order Number 00-09 establishing the Home and Community-Based Services and Consumer-Directed Care Commission. The Commission is comprised of 15 persons representing consumers of community-based services, members of the Governor's Council on Disabilities, Legislators and state agencies. The Commission was charged with reviewing Missouri's community based and consumer directed services and developing a comprehensive and effective working plan to ensure that persons with disabilities are offered effective choices in their supports and services. The plan was to give recommendations for compliance with the United States Supreme Court ruling in the Olmstead case based on protections under the Americans with Disabilities Act.

The Commission approached the development of the plan in a very open and inclusive manner with public hearings across the state and public comment taken at each commission meeting. In developing the plan the Commission drew upon the previous work of many stakeholders who had spent months working on Olmstead issues. Four subcommittees with over 150 persons participating developed recommendations to the Commission as it developed the report and recommendations. All together, over 600 persons participated in the process contributing their valuable time and effort. The Commission members want to thank all of the people who contributed so much to the development of this report.

Missouri has made great progress in developing a flexible and consumer-driven service system. Over the past few years steps have been taken to strengthen Missouri's programs, but as our report reflects, there are many challenges ahead. We believe these challenges will be met by following the set of recommendations outlined here. They can be found in greater detail along with background documentation in the complete "Working Plan."

Commission members ended at the beginning, reaffirming their belief that the goal is to allow people with disabilities choices about where they live, to make those choices real and to make them available. The Commission's principle is people belong at home, and in most cases that is the most integrated setting. In most cases, home should be of your own choosing.

Major Recommendations

Caregiver Compensation

The rate of reimbursement has got to be looked at. What these aides do is phenomenal. (Kirksville Public Hearing)

The Commission heard about this issue in every hearing and meeting. It is a universal issue across all programs and of great significance. While this is a challenging issue, the Commission is encouraged about the state's initiative in establishing a Caregivers Workforce Task Force to study it and make recommendations, and the state agencies following through in their budget requests. We endorse the Caregivers Workforce Task Force recommendations and the state agencies' supporting budget requests. Our recommendations include:

- Pay increases of \$2 per hour each of the next three years for wages and benefits of direct caregivers.
- Increase access to health care coverage, child-care and other supports for caregivers.
- Career ladders for caregivers in state supported programs need to be developed to support retention and develop greater opportunities.

Housing

There isn't enough housing . . . The availability of quality, accessible and affordable housing within the communities of the individuals' choice is lacking. (Kansas City Public Hearing)

We heard constantly about the need for affordable, safe housing that is accessible to persons with disabilities. There was recognition that the state had taken initial steps in securing housing through its waiver and other specialized programs over the past several years. There is still a strong need in all programs to strengthen community services and placements and housing is a major barrier to these efforts. The issue is made all the more difficult because housing is traditionally not a state funded program and federal Medicaid law does not allow payment for housing. In addition, inadequate transportation makes accessing some housing or services all the more difficult.

- Any housing program receiving any state funds must build or rehab using universal design codes for disabled access.
- The state should encourage federal law changes to allow Medicaid to pay for housing where it is shown to be cost effective and avoids institutionalization.
- Transportation systems for people with disabilities must be developed and strengthened that support community living.

Informed Choice

I've been disabled since June, so I don't know any of this. So I need to be informed. How can I be informed? . . . If you don't know what choice you have, you have no choice. (Springfield Public Hearing)

We identified the need to make sure consumers both in and out of institutions have information available to make good, rational informed choices about where they want to live. Inherent in this process is the need for a wide variety of choices for people with tremendously varying disabilities and that they know their rights in making choices. It is critical that state and other staff involved in the process receive good training on this issue and that it be ongoing and updated because of the turnover of staff and continuous revision in laws and programs. The commission also identified the need to inform judges, public administrators, attorneys and others involved in the process of guardianship issues about the wide range of options now available supporting people with disabilities in their efforts to remain in the community. While the laws are there to protect the rights of consumers with guardians, they are not well known. Perhaps even more importantly, judges are often not well versed on how successful community settings are and the availability of programs and supports.

Consumers should be able to make informed choices about where they live and state programs and staff must have processes to support and document this choice.

Uniform training and good useable information about choice must be available for state and public/private agency and advocate staff involved in the choice process.

Training and continuing education programs on home and community programs and resources must be available for judges and others in the legal guardianship process.

Consumer and Family Directed with Supportive and Flexible Funding

I believe it would be in the best interest of the persons with disabilities everywhere if we could get funding for HB 1111 program or Olmstead program that lets the person hire the caregiver they want . . . It is in the best interest of the individual. (St Louis Public Hearing)

It was noted again and again and again that both Medicaid and Mental Health funding had taken significant initial steps in the direction of flexible funding and consumer direction. The Commission strongly supports these efforts and their expansion to additional populations and to include new services under consumer directed. It was acknowledged that professional practice acts in the state do not always support these efforts, and work needs to be done to update them for the current service delivery environment.

Missouri should expand consumer directed care to additional programs.

· Additional services now restricted to agencies should be added to consumer directed programs.

- Advance practice acts should be reviewed with recommendations to allow for more services to be provided by personal care attendants in keeping with today's consumer needs and desires for who can best meet those needs.

Defining "Institutionalization"

State agencies have done a good job of keeping waiting lists for people in state institutions who want to return to the community. In addition, the commission applauds Missouri for recognizing that people should not have to first go into an institution to be eligible for community placement and services. Missouri has become a national leader in working to help those discharged from the hospital return home in the aging world and is working to help people with disabilities avoid institutional placement. The Commission did identify a deficiency in looking at waiting lists for services for those in private facilities that are publicly funded. We strongly recommend that more work in this area needs to be done.

- State agencies need to expand their definition of institutions to include private placement resources that they contract with or otherwise pay for residential services and collect data on these consumers.
- Persons with disabilities in all institutions should be assessed for home and community placement and services and given an informed choice about their options.

Expanding Opportunities for Support and Employment by Expanding Medicaid Eligibility

I would love to go to work tomorrow and I could go to work tomorrow if it wasn't for the fact that my medical condition and needing Medicaid. Until we can take hold and receive economic power to be able to have control over our own lives from an economic standpoint . . . things are not going to change. (Springfield Public Hearing)

It is believed that Missouri has the lowest resource test for Medicaid in the nation and one of the lowest income tests. In addition, there are several new options for Medicaid expansions for people with disabilities as well as for working parents with low income. Today's private and employer based health insurance world does not work for these populations. Expanding Medicaid eligibility makes good economic sense for the state. It allows people to work and be productive citizens and supports families staying together, all while maximizing federal dollars and supporting jobs in the health care arena.

- The available asset and income tests for Medicaid should be increased to allow for greater coverage and less reliance on the confusing but essential spend-down program.
- Missouri should expand Medicaid to include the Ticket To Work Option, including the buy-in provision for higher income disabled.
- Missouri should expand Medicaid under section 1931 of the Social Security Act to allow families below 100 percent of the federal poverty level to access health care coverage.

Identifying and Assessing Waiting Lists and Developing Guidelines for Their Movement in Each Program Area

Measure the rate of persons moving into the community at the end of the year. (Sub-committee Recommendation)

There was considerable conversation about waiting lists for services. There are approximately 6,500 people on various waiting lists for home and community services across three departments. State agencies do not have good information on people waiting for community services living in contracting providers in the mental health system. In addition, waiting lists cannot account for those who are unaware of programs and so never apply, something common to all agencies. The Commission believes more work needs to be done by each agency in assessing their waiting lists and developing roadmaps for consumer movement into services. This process must include strict timeframes for activities and periodic reviews and must account for those served through contracted providers. This will be particularly important as better information about programs and choices may have a significant impact on service demand.

- There should be a goal of assessing people with disabilities who are institutionalized or eligible to be institutionalized within 30 days of placement or application for services, and the assessment should be documented.
- There should be at least a yearly re-assessment and documentation for those who remain eligible for and choose institutionalization.
- Where the assessment or re-assessment determines home or community placement is appropriate the consumer should be moved within 90 days. Where this goal is not met, the reason must be documented in the record with progress reviewed and documented monthly thereafter. Agencies must have available a report on the results of this process quarterly.

Ongoing Monitoring and Reporting Mechanism

I think a final challenge facing you all is to develop an evaluation plan that will help the commission determine if your recommendations are having a positive effect and positive outcomes for our clients who choose community-based living and community-based services. (Commission Hearing, 11/13/00)

The Commission and the public have identified the need for ongoing review of the state's home and community-based services and consumer-directed care programs. Much discussion was held around how best to do this. Because of the structure of state government and the diverse nature of these programs, it is not practical or efficient to place one department in charge of them. In addition, no single current state commission covers the wide spectrum of viewpoints and expertise that the make-up of our Commission represents. After much thought we are recommending the Governor continue the Commission to review, assess, and report on Missouri's progress in better serving people under Missouri's home and community-based and consumer-directed care programs. This will help Missouri fully implement programs supporting the Olmstead decision, the American with Disabilities Act and subsequent related directives from the US Department of Health and Human Services.

- The Governor should establish an ongoing Commission on Home and Community-Based Services and Consumer-Directed Care.

Complete Listing of Recommendations

The following is a complete summary listing of all recommendations in the body of the plan. These are shown in the order in which they appear in the plan, not the order of significance. All recommendations refer to implementing the plan for better serving people with disabilities unless otherwise specified.

1. One department or entity should take leadership in developing effective assessment outcome measures.
2. Measure the rate of community placements yearly, as well as barriers to placements.
3. Develop a process evaluation and measure plan implementation yearly.
4. Develop a provider profile to be used by consumers in making choices.
5. Identify the number of staff trained on informed choice and how they use the training.
6. Develop processes to interview individuals to determine if they had informed choice.
7. Improve pre institutionalization assessment, screening and staff training processes.
8. Additional screening and training is needed regarding persons with disabilities.
9. One department or entity should develop a single document outlining available services.
10. A consumer satisfaction survey process should be implemented and used in oversight.
11. Develop statewide Olmstead training for state, agency and provider staff.
12. Statewide training should encourage networking and offer continuing education credits.
13. With consumer input, state agencies should develop and promote train-the-trainer programs.
14. Information should be available through a toll-free hotline marketed to the public.
15. Informed choice information and confirmation forms should be given to all consumers.
16. State agencies should develop verification processes to assure informed choice is given.
17. Multidisciplinary teams should include a person knowledgeable about independent living.
18. A clearly defined appeal procedure shall be part of the choice process.
19. The Division of Aging should look for ways to enable in-home agencies to work after “normal” working hours.
20. Increase consumer controlled options and train people with disabilities to be attendants.

21. Train consumers on how to coordinate, negotiate, purchase, direct, hire and fire attendants.
22. Increase wages/benefits of caregivers by \$2 per hour each of the next three years.
23. Direct caregivers need minimum of 20 hours of on-the-job training and credentialing.
24. Develop and use a skill (competency) standard for caregivers.
25. Clarification needed about the legality of attendants to assist with some personal care health care tasks under the nurse practice act. If not allowable, the Act needs changing to allow.
26. A background screening must be performed on all direct caregivers to protect consumers.
27. The Fair Housing Amendments need better enforcement and all available housing resources should be accessed to the fullest.
28. Better, more accurate information on available housing must be available for people needing immediate placement.
29. The Governor's Council on Disability should establish a "People with Disabilities" web page to provide timely consumer information.
30. Increase Missouri's use of supportive housing for persons with disabilities (Section 811).
31. Explore use of Section 8 program to purchase homes.
32. Increase the use of supportive housing for persons who are elderly (Section 202).
33. Explore the possibility of using Medicaid to pay for housing.
34. Explore a Housing Disabled Access Tax Credit.
35. Explore development of a tax credit for builders who meet certain access standards.
36. Develop a grant program for needed home modifications for emergency assistance.
37. Explore a "visitability" law to require entities awarded state/federal funds to build single-family dwellings must include accessibility features.
38. Include housing specialists to work on future Olmstead implementation and planning.
39. Increase availability of scattered site accessible housing. Change parameters of state and local service dollars to include housing.
40. Change parameters of state and local service dollars to include housing.
41. Explore inclusion of accessibility provisions in the recommendations of the Governor's Commission for the Review and Formulation of Building Code Implementation.
42. Enhance public/private partnerships to improve availability of affordable accessible housing. Establish, market and provide consumer assistance for the low interest loan program for assistive technology including housing modifications.
43. Establish, market, and provide consumer assistance for the low interest loan program for assistive technology including housing modification.

44. Any housing program receiving any state funds must build or rehab using universal design codes for disabled access.
45. Increase revenue in the Housing Trust Fund, and increase the uses for the fund.
46. Encourage communities with Consolidated Housing Plans to use the universal design concept and prioritize housing for persons with disabilities.
47. Explore with the Missouri Housing Development Commission methods to encourage local governments to address home accessibility needs.
48. State agencies should have data linkages and shared information.
49. Where multiple agencies serve a consumer, a lead agency should be named.
50. Service coordinators need ongoing training to understand all services in a plan.
51. There should be one central phone number for information about community services.
52. Develop a universal application form for home and community services across agencies.
53. Create a universal chart outlining the various community services and criteria for each.
54. Allow for blended funding streams between all programs and agencies.
55. Increase the resource limit for Medicaid to \$4,000 for an individual.
56. Exempt ore assets from Medicaid's eligibility test and lobby HCFA for increased state flexibility in determining eligibility.
57. Explore covering all Medicaid waiver services as state plan services.
58. Expand current Medicaid waivers to cover all people on waiting lists where cost neutrality can be maintained.
59. Monitor waiting lists and document why someone is on one longer than 90 days.
60. To assist adults with head injury, budget authorization for the submission of a Medicaid Waiver will be requested.
61. Medicaid should pay to retain a personal attendant while the consumer is temporarily out of the home.
62. Expand the protection of spousal assets and income in all Medicaid HCBS waivers.
63. Consider exercising the TEFRA 134 option to expand Medicaid to additional children with disabilities by disregarding their parent's income and assets.
64. Increase Medicaid income limits to 100% of poverty for the disabled and elderly.
65. Increase HCBS Medicaid income limits to 300% of Supplemental Security Income.
66. Lobby HCFA to allow for Medicaid transition funding for persons in an Institution for Mental Disease.
67. Expand the definition of allowable services in Personal Assistance Services (PAS).
68. Expand current Medicaid waivers to allow more hours of PAS where cost neutrality is maintained.

69. Amend state plan to allow all PAS options to be used on the job.
70. Implement the Ticket to Work and Work Incentives Improvement Act, including the buy-in provision.
71. Olmstead transition funding through the Governor's Council on Disability to help people leave nursing home.
72. Expand private donated funding and materials opportunities to help people have nursing homes.
73. Work for discretionary funding to cover emergencies and unique circumstances to help people leave nursing homes.
74. Local school districts should review and meet the Olmstead requirements.
75. The Missouri SB321 (Transition Advisory Council) should be fully funded.
76. Person centered planning should be implemented for everyone transitioning from an institution to the community.